

## Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience" Scroll down to [Specialist Publications](#) and 'The acceptability of humor between palliative care patients and health care providers' (p.7) in *Journal of Palliative Medicine*.

## Canada

### Alzheimer's patient's desire to die denied by B.C. court, family says she is force fed by nursing home

BRITISH COLUMBIA | *The National Post* – 5 February 2014 – Ever since she entered the latter stages of Alzheimer's disease, 82-year-old Margot Bentley has received her nourishment by spoon. At meal times, an attendant at Abbotsford, B.C.'s Maplewood House care home places spoonful after spoonful against Ms. Bentley's lower lip, waits for the woman to open her mouth, then gently nudges the food inside. When Ms. Bentley stops opening her mouth, the attendant takes it as a signal she is full. It is a routine task performed in hundreds of care homes across Canada, but according to Ms. Bentley's family, the daily meals are a kind of force-feeding keeping the severely demented woman alive against her wishes – specifically, a two-decades-old official request she be denied "nourishment or liquids" were she ever to reach such a condition. But, in a decision that could have a profound

effect on Canadian end-of-life care, the Supreme Court of British Columbia officially disagreed, arguing by opening her mouth Ms. Bentley is demonstrating a will to live. <http://news.nationalpost.com/2014/02/04/alzheimers-patients-desire-to-die-denied-by-b-c-court-family-says-she-is-force-fed-by-nursing-home/>

#### Extract from *The National Post* article

"Mrs. Bentley is ... providing her consent through her behaviour when she accepts nourishment and liquids," wrote Supreme Court Justice Bruce Greyell in a 44-page decision. He also rejected the claims of Ms. Bentley's doctor that the woman's acceptance of the food is merely reflex. Instead, Justice Greyell dubbed it "communication through behaviour, which is the only means through which Mrs. Bentley can communicate."

Noted in Media Watch, 12 August 2013, #318 (p.1):

- BRITISH COLUMBIA | *The Vancouver Sun* – 6 August 2013 – '**Patient's family sues B.C. as nursing home keeps her alive against her wishes.**' The lawsuit is expected to be precedent-setting as it should clarify end-of-life rights of patients and obligations of health providers. <http://www.vancouversun.com/health/Patient+family+sues+Victoria+over+living+will/8756167/story.html>

## U.S.A.

### **The cost of dying: It's hard to reject care even as costs soar**

CALIFORNIA | *The Contra Costa Times* (Walnut Creek) – 4 February 2014 – Every night before putting on his pajamas, Dad emptied the coins from his pockets. The special ones he placed in an album, but most went into a jar to be saved. So how could the hospital bill for the final days of this frugal man – with carefully prepared end-of-life instructions – add up to \$323,000 in just 10 days? That's the price of a home for a struggling family. Enough to put a future doctor through medical school. Hundreds of prenatal visits. Thousands of vaccinations. My father's story – the final days of a frail 88-year-old with advancing dementia at the end of a long and rewarding life – poses a modern dilemma: Just because it's possible to prolong a life, should we? It's a story of people doing their best in a system that's built to save our loved ones. And it's a reminder of the impossibility, during a crisis, to assess costs and benefits that aren't at all obvious. This was the lesson of my father's passing: It is easy to get quick access to world-class treatment. It's much harder to reject it. <http://dfm.contracostatimes.com/article/the-cost-of-dying-its-hard-to-reject-care-even-as-costs-soar/debd68c039dd7cc7d2024ba5e8993c55>

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- *THE NEW YORK TIMES* | Online – 7 February 2014 – **"Aid in dying" movement takes hold in some states.** Helping the terminally ill end their lives, condemned for decades as immoral, is gaining traction. Banned everywhere but Oregon until 2008, it is now legal in five states. Its advocates, who ... shun the term "assisted suicide," believe that as baby boomers watch frail parents suffer, support for what they call the "aid in dying" movement will grow further. <http://www.nytimes.com/2014/02/08/us/easing-terminal-patients-path-to-death-legally.html>

## International

### End-of-life care in India

### **Shun political differences, pass law on opioids for patients: Doctors**

INDIA | *The Times of India* (New Delhi) – 5 February 2014 – The Narcotic Drugs & Psychotropic Substances (Amendment) Bill, 2011, aimed at ensuring the availability of essential narcotic drugs for medicinal use for patients in need is pending in parliament... Doctors across the country involved in palliative care have urged parties to set aside their differences to pass this "entirely non-political bill" for the sake of millions suffering from unbearable pain due to lack of access to medicines made from narcotics substances. <http://timesofindia.indiatimes.com/india/Shun-political-differences-pass-law-on-opioids-for-patients-Doctors/articleshow/29878369.cms>

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### Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Noted in Media Watch, 27 January 2014, #342 (p.6):

- HUMAN RIGHTS WATCH | *World Report 2014* – 23 January 2014 – **'Palliative care: International perspective.'** After a series of positive steps in 2012 to address the suffering of hundreds of thousands of persons with incurable diseases from pain and other symptoms, progress on palliative care in India slowed considerably in 2013. The government has so far not allocated a budget to implement India's progressive national palliative care strategy and parliament failed to consider critical amendments to the Narcotic Drugs & Psychotropic Substances Act that would dramatically improve the availability of strong pain medications. More than 7 million people in India require palliative care every year (p.338 of *World Report 2014*). [http://www.hrw.org/sites/default/files/wr2014\\_web\\_0.pdf](http://www.hrw.org/sites/default/files/wr2014_web_0.pdf)

### [Specialist Publications](#)

**'Strengthening international networks to advance global palliative care'** (p.5), in *Illness, Crisis & Loss*.

Of related interest:

- INDIA (Odisha) | *The New Indian Express* (Bhubaneswar) – 6 February 2014 – **'Palliative care services to reach doorsteps.'** The [state] Government will roll out the National Programme for Palliative Care in 10 districts... The programme envisages not only establishing pain and palliative care centres at the district headquarters hospitals but also create a pool of trained workforce to deliver home-based services to cancer and other terminally ill patients. [http://www.newindianexpress.com/states/odisha/Palliative-Care-Services-to-Reach-Doorsteps/2014/02/06/article2041231.ece#\\_UvObYmJdX8k](http://www.newindianexpress.com/states/odisha/Palliative-Care-Services-to-Reach-Doorsteps/2014/02/06/article2041231.ece#_UvObYmJdX8k)

### [End-of-life care in Ireland](#)

#### **Draft legislation for Bill allowing terminally ill to make "living wills"**

IRELAND | *The Irish Times* (Dublin) – 5 February 2014 – The government has published draft legislation for a Bill to allow terminally ill people to make "living wills" setting out treatments they wish, and do not wish, to have at the end of their lives. Minister for Health James Reilly brought the general scheme of the Assisted Decision-Making Capacity Bill to government, where it was approved by cabinet colleagues. The draft Bill will be published and sent out for public consultation. The responses and submissions received will be debated and discussed by the Oireachtas [the national parliament] Committee on Health in advance of the final Bill being published. <http://www.irishtimes.com/news/politics/draft-legislation-for-bill-allowing-terminally-ill-to-make-living-wills-1.1679634>

#### **Hundreds of cancer patients in England & Wales to be denied life-prolonging drug – but patients in Scotland will still get it**

U.K. (England & Wales) | *The Daily Mail* – 5 February 2014 – Hundreds of lung cancer patients in England & Wales are to be denied a life-prolonging drug that will remain available in Scotland. For the last five years Tarceva® has been an option for around 1,000 lung cancer sufferers a year after chemotherapy has failed. But the National Health Service rationing watchdog has decided to change its guidance, which experts say will send cancer care "backwards." The National Institute for Health & Care Excellence has re-reviewed its existing guidance after the chemotherapy drug against which Tarceva was compared went off-patent, leading to a lower price. <http://www.dailymail.co.uk/health/article-2552086/Hundreds-cancer-patients-England-Wales-denied-life-prolonging-drug-patients-SCOTLAND-it.html>

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Noted in Media Watch, 2 September 2014, #321 (p.10):

- *JOURNAL OF HEALTH POLITICS, POLICY & LAW* | Online – 23 August 2013 – '**Can the NICE "end-of-life premium" be given a coherent ethical justification?**' In 2009 the U.K. National Institute for Health & Clinical Excellence (NICE) announced that its health technology appraisal committees would henceforth give special additional weight to health gains from life-extending end-of-life treatments. This was a response to mounting concern from NICE's stakeholders that effective new drugs for end-stage cancer often fail NICE's standard test of cost effectiveness. <http://jhpl.dukejournals.org/content/early/2013/08/20/03616878-2373166.abstract>

### **Councils in England "pay too little for home care"**

U.K. (England) | BBC News – 4 February 2014 – Most councils in England are paying less than the industry recommended minimum for personal home care, a BBC investigation suggests. The U.K. Homecare Association, which represents providers, want them to be paid a minimum of £15.19 an hour, to cover wages, training and travel. But data obtained under the Freedom of Information Act found the minimum paid met that in just four out of 101 cases. The investigation, by BBC Radio 4's 'File on 4' programme, found the average minimum rate paid by councils was £12.26 an hour. Home care services are paid for by councils – and often delivered by agencies – to the elderly and younger disabled adults in their own homes if they qualify through a means-tested assessment. <http://www.bbc.co.uk/news/uk-26021026>

### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- U.K. | The Christian Institute – 4 February 2014 – '**Poll: Support for ending euthanasia by dehydration.**' A new poll has found that over half of the British public are against doctors euthanizing patients by dehydration, if they have asked prior to incapacitation to be kept alive.<sup>1</sup> Under the Mental Capacity Act 2005, doctors can withdraw water from patients if it is deemed in their "best interests" and if they think death is approaching soon. But the ComRes survey ... shows that 58% of people favour a change to this law. They want patients – who request artificial hydration ahead of being incapacitated – to have their wishes upheld by doctors. <http://www.christian.org.uk/news/poll-support-for-ending-euthanasia-by-dehydration/>

1. Mental Capacity Act Survey, ComRes, January 2014. [http://www.comres.co.uk/polls/Alert\\_Mental\\_Capacity\\_Act\\_Public\\_Poll\\_17th\\_January\\_2014.pdf](http://www.comres.co.uk/polls/Alert_Mental_Capacity_Act_Public_Poll_17th_January_2014.pdf)

### **Specialist Publications (e.g., in-print and online journal articles, reports, etc.)**

#### **Improving end-of-life care in hospitals: A qualitative analysis of bereaved families' experiences and suggestions**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 February 2014 – Families described structural deficiencies. They requested a more holistic patient health care beyond medical treatment and expressed the wish for more professional support for families. The view of bereaved families confirmed the need for improvement in general hospital EOL [end-of-life] care. <http://ajh.sagepub.com/content/early/2014/02/07/1049909113512718.abstract>

Noted in Media Watch, 20 May 2013, #306 (p.15):

- *PALLIATIVE MEDICINE* | Online – 13 May 2013 – '**Patient and family experiences of palliative care in hospital: What do we know? An integrative review.**' This review has identified that ... our knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. Further research is required ... taking into account all aspects of care including potential benefits of hospital admissions in the last year of life. <http://pmj.sagepub.com/content/early/2013/05/10/0269216313487568.abstract>

**"There won't be anything else ... it's over":  
Perceptions of women referred to palliative care only**

*EUROPEAN JOURNAL OF NURSING ONCOLOGY* | Online – 31 January 2014 – Three categories were identified in the [study] participants' narratives: 1) an understanding of the meaning of palliative care; 2) a lack of understanding of the shift in treatment and follow-up; and, 3) differing perspectives about hope. The palliative care unit was stigmatized as a place to die... The narratives of the participants who previously had experienced palliative care ... reveal recognition of the importance of the palliative care unit as "a place that enhances the quality of life."  
[http://www.ejoncologynursing.com/article/S1462-3889\(14\)00012-X/abstract](http://www.ejoncologynursing.com/article/S1462-3889(14)00012-X/abstract)

**Strengthening international networks to advance global palliative care**

*ILLNESS, CRISIS & LOSS*, 2014;22(1):3-10. As palliative care has matured as a discipline, the impact of working with individuals at the end of life has become more visible. In turn, palliative care professionals have developed ways to share their respective experiences and a number of representative worldwide groups have emerged. These groups have become increasingly involved in advocacy and awareness-raising activities on behalf of the sector, using rights-based arguments and a public health framework to advocate for equitable access to palliative care. This article provides an overview of some of the work that has been undertaken by international groups. Although worldwide activities may differ in emphasis, there has been demonstrated benefit in coalescing the advocacy activities, in order to present a united global voice on issues.  
<http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,11;journal,1,77;linkingpublicationresults,1:103734,1>

**N.B.** 'Global Atlas of Palliative Care at the End of Life,' World Health Organisation and the Worldwide Palliative Care Alliance, January 2014. [Noted in Media Watch, 3 February 2014, #343 (p.5)]  
<http://www.thewpca.org/resources/global-atlas-of-palliative-care/>

Of related interest:

- *EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING* | Online – 28 January 2014 – '**Do inequalities in end-of-life care matter?**' Further explication of the prerequisites, processes and outcomes of palliative care for people at the end of life, including those with complex chronic life-limiting conditions, the frail elderly and other groups with special needs might challenge the provision of palliative care. Since models for providing palliative care partly were developed decades ago and partly tailored for people with cancer, up-to-date knowledge will form a significant basis for the development of models applicable tomorrow for palliative care that at least moderates the inequities we recognize today. In order to accomplish such progress, there is an urgent need for creative collaboration between practitioners and researchers for the development of modes, approaches and models for end-of-life care responding to palliative care needs of individuals of all ages, independent of diagnosis and living circumstances.  
<http://cnu.sagepub.com/content/early/2014/01/28/1474515114521952.full>

**Deathbed wills: Assessing testamentary capacity in the dying patient**

*INTERNATIONAL PSYCHOGERIATRICS*, 2014;26(2):209-216. Deathbed wills by their nature are susceptible to challenge. Clinicians are frequently invited to give expert opinion about a dying testator's testamentary capacity and/or vulnerability to undue influence either contemporaneously, when the will is made, or retrospectively upon a subsequent challenge, yet there is minimal discourse in this area to assist practice. Dying testators are vulnerable to delirium and other physical and psychological co-morbidities. Delirium, highly prevalent amongst terminal patients and manifesting as either a hyperactive or hypoactive state, is commonly missed and poorly documented. Whether the person has testamentary capacity depends on whether they satisfy the *Banks v Goodfellow* [1870] legal criteria and whether they are free from undue influence.  
<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9145726>

## Strategic targeting of advance care planning interventions: The Goldilocks phenomenon

*JAMA INTERNAL MEDICINE* | Online – 3 February 2014 – Strategically selecting patients for discussions and documentation about limiting life-sustaining treatments – choosing the right time along the end-of-life trajectory for such an intervention and identifying patients at high risk of facing end-of-life decisions – can have a profound impact on the value of advance care planning (ACP) efforts. Timing is important because the completion of an advance directive (AD) too far from or too close to the time of death can lead to end-of-life decisions that do not optimally reflect the patient's values, goals, and preferences: a poorly chosen target patient population that is unlikely to need an AD in the near future may lead to patients making unrealistic, hypothetical choices, while assessing preferences in the emergency department or hospital in the face of a calamity is notoriously inadequate. Because much of the currently studied ACP efforts have led to a disappointingly small proportion of patients eventually benefitting from an AD, careful targeting of the intervention should also improve the efficacy of such projects. A key to optimal timing and strategic selection of target patients for an ACP program is prognostication, and we briefly high-light prognostication tools and studies that may point us toward high-value AD interventions. <http://archinte.jamanetwork.com/article.aspx?articleid=1819576>

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### Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

### Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Updated 7 February 2014

### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.12.

Of related interest:

- *ILLNESS, CRISIS & LOSS*, 2014;22(1):11-27. **'Wading in the water: A case study approach to engaging more fully in the patient narrative.'** The complexity of engaging in end-of-life conversations, standing steady with conflict, remaining present, maintaining neutrality, and actively listening, remain challenging concepts in practice even though they are integral to effectively doing so. Literature review has identified and defined key elements of interactions that can lead to significant opportunities to "wander more fully" in the patient narrative. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,11;journal,1,77;linkingpublicationresults,1:103734,1>
- *PATIENT PREFERENCE & ADHERENCE* | Online – 24 January 2014 – **'Advance care planning in stroke: Influence of time on engagement in the process.'** In this study, the authors found open and continual ACP [advance care planning] conversations were not taking place, patients experienced an apparent lack of urgency to engage in ACP, and health care professions were uncomfortable initiating ACP conversations due to the sensitive nature of the topic. <http://www.dovepress.com/advance-care-planning-in-stroke-influence-of-time-on-engagement-in-the-peer-reviewed-article-PPA>

#### **End-of-life care in Germany**

#### **"Please describe from your point of view a typical case of an error in palliative care": Qualitative data from an exploratory cross-sectional survey study among palliative care professionals**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 February 2014 – Patient safety is a concern in medicine, and the prevention of medical errors remains a challenge. The definition and understanding of an error is particularly difficult in palliative care, with scarce empirical evidence about the nature and causes of medical errors in that discipline. This study explored incidents palliative care professionals perceive as typical errors in their practice, and descriptions of such events. Seven potential areas for errors were identified: drug treatment, palliative sedation, communication, care organization, treatment plan, end-of-life care, and history taking. Six categories emerged as causes of errors: miscommunication, system failure, dysfunctional attitudes, lack of knowledge,

wrong use of technology and misjudgement. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0356>

#### **Extract from *Journal of Palliative Medicine* article**

Data showed that medical errors in palliative care, as seen by professionals in the field, primarily affect medication and communication, and miscommunication and system failures are perceived as the leading causes of errors. A better understanding of the characteristics of errors within palliative care and further qualitative research are warranted to prevent errors and enhance patient safety.

#### **The acceptability of humor between palliative care patients and health care providers**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 February 2014 – Humor frequently occurs in palliative care environments; however, the acceptability of humor, particularly between patients and health care providers has not been previously examined. A large majority of participants [in this study] valued humor highly both prior to (77%) and during (76%) their illness experience. Despite this valuation, the frequency of laughter in their daily lives diminished significantly as patients' illness progressed. Most participants remembered laughing with a nurse (87%) and a doctor (67%) in the week prior to the survey, and found humor with their doctors (75%) and nurses appropriate (88%). The majority of participants found humorous interactions with their health care providers acceptable and appropriate, and this may indicate a opportunity for enhanced and more effective end-of-life care in the future. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0354>

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Representative sample of articles on humor in the palliative care setting noted in past issues of Media Watch:

- *HEALTH EXPECTATIONS* | Online – 2 January 2012 – '**Humour in health-care interactions: A risk worth taking.**' Patients [i.e., study participants] hold a broad appreciation of humour and recognize it as being evident in subtle and nuanced forms. Patients wish health-care staff to initiate and reciprocate humour. A chasm exists between what patients apparently want with regard to humour use in health-care interactions and what actually transpires. Initiating humour involves risk, and risk-taking requires a degree of self-esteem and confidence. Nurses are, arguably, risk-averse and have low self-esteem. [Noted in Media Watch, 9 January 2012, #235 (p.9)] <http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2011.00758.x/abstract>
- *JOURNAL OF CLINICAL NURSING*, 2008;17(8):1088-1095. '**From critical care to comfort care: The sustaining value of humour.**' Studies identify situations involving serious discussion, life-threatening circumstances and high anxiety as places where humour may not be appropriate. The authors of this article demonstrate humour is significant even where such circumstances are commonplace. Humour serves to enable co-operation, relieve tensions, develop emotional flexibility and "humanise" the health-care experience for both caregivers and recipients of care. [Noted in Media Watch, 30 April 2012, #251 (p.13, under 'Worth Repeating')] <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2007.02090.x/full>

### Cultural considerations at the end of life

*NURSE PRACTITIONER*, 2014;39(2):24-32. It is important for nurse practitioners to understand patients' cultural backgrounds to provide competent care at the end of life. Understanding the concepts of various cultures can keep the lines of communication open and help providers elicit the necessary information to make the end-of-life experience as comfortable as possible. The authors discuss the importance of culture in care; cultural assessment; Black American, Hispanic, Chinese American and Muslim cultures; and, interventions and approaches to culture and care. [http://journals.lww.com/tnpj/Fulltext/2014/02000/Cultural\\_considerations\\_at\\_the\\_end\\_of\\_life.7.aspx](http://journals.lww.com/tnpj/Fulltext/2014/02000/Cultural_considerations_at_the_end_of_life.7.aspx)

Noted in Media Watch, 3 June 2013, #308 (p.10):

- *HEALTH CARE ANALYSIS* | Online – 30 May 2013 – '**Understanding and coping with diversity in healthcare.**' In the healthcare sector, race, ethnicity and religion have become an increasingly important factor in terms of patient care due to an increasingly diverse population. Health agencies at a national and local level produce a number of guides to raise awareness of cultural issues among healthcare professionals and hospitals may implement additional non-medical services, such as the provision of specific types of food and dress to patients or the hiring of chaplains, to accommodate the needs of patients with religious requirements. recognize that a diverse range of views and practices exist within specific groups themselves. <http://link.springer.com/article/10.1007/s10728-013-0249-0>

### Using Skype® to support palliative care surveillance

*NURSING OLDER PEOPLE*, 2014;26(1):16-19. The author presents a case study as an in-depth example of the use of Skype® in the context of palliative care at home. Skype® enhanced family surveillance and symptom management, augmented shared decision making, provided a space for virtual bedside vigil, and ultimately provided the rapport necessary for optimal end-of-life care. <http://rcnpublishing.com/doi/abs/10.7748/nop2014.02.26.1.16.e546>

Noted in Media Watch, 9 April 2012, #248 (p.4):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 March 2012 – '**From Cork to Budapest by Skype®: Living and dying.**' The availability of Skype® enables patients and families to communicate across wide geographical boundaries, particularly advantages in situations where family members cannot routinely attend at the hospital because of other commitments or distance. <http://spcare.bmj.com/content/early/2012/03/31/bmjspcare-2012-000210.abstract>

## **The European Association for Palliative Care basic dataset to describe a palliative care cancer population: Results from an international Delphi process**

*PALLIATIVE MEDICINE* | Online – 6 February 2014 – A total of 64 experts from 30 countries participated. High consensus was reached on 31 variables, divided between a "patient form" – date of birth, gender, living situation, education, ethnicity and 12 symptoms – and a "health-care personnel form" – patient's date of birth, principal diagnosis, date of the principal diagnosis, stage of the cancer disease, site of metastases, present anticancer treatment, main additional diagnoses, stage of the additional diagnoses, medication, weight loss, performance status, cognitive impairment, place of care and provision of care. It was more difficult to agree upon how to record the variables, but consensus was reached on all except ethnicity, vomiting and weight loss. <http://pmj.sagepub.com/content/early/2014/02/06/0269216314521264.abstract>

### **Building the evidence base for palliative care and dementia**

*PALLIATIVE MEDICINE*, 2014;28(3):195-196. There is growing recognition among clinicians, researchers, and policy makers of the need for high-quality palliative care for patients with dementia. This recognition is increasing as evidence mounts that dementia is a terminal disease and that patients have many unmet needs for palliative care. Dementia care requires a specialized knowledge base since the disease course and symptoms differ in important ways from other conditions. For example, the disease trajectory of dementia is marked by a slow, gradual decline in function and differs from the trajectory in cancer or cardiopulmonary disease. There is also a high prevalence of neurobehavioral symptoms that provide management challenges. Also, caregivers play a unique role since they must take over disease management and decision making as dementia progresses. While patients suffer from high levels of pain and other symptoms commonly associated with diseases such as cancer, treatment may be complicated by patients' cognitive impairment. Three articles from this edition of *Palliative Medicine* add to our knowledge base and provide guidance for clinicians seeking to improve palliative care quality for patients with dementia.<sup>1,2,3</sup> <http://pmj.sagepub.com/content/28/3/195.full>

1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, 2014; 28(3):197-209. [First published 4 July 2013; Noted in Media Watch, 8 July 2013, #313 (p.10)] <http://pmj.sagepub.com/content/28/3/197.full.pdf+html>
2. 'When do people with dementia die peacefully? An analysis of data collected prospectively in long-term care settings,' *Palliative Medicine*, 2013;28(3):210-219. <http://pmj.sagepub.com/content/28/3/210.abstract>
3. 'Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over,' *Palliative Medicine*, 2013;28(3):220-233. [First published on 6 December 2013; Noted in Media Watch, 9 December 2013, #335 (p.13)] <http://pmj.sagepub.com/content/28/3/220.full.pdf+html>

#### **[Media Watch posted on Palliative Care Network-e Website](#)**

Palliative Care Network-e promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap – to foster teaching and interaction, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

## The duty of the physician to care for the family in pediatric palliative care: Context, communication and caring

*PEDIATRICS*, 2014;133(Suppl1):S8-S15. Pediatric palliative care physicians have an ethical duty to care for the families of children with life-threatening conditions through their illness and bereavement. This duty is predicated on two important factors: (1) best interest of the child; and, (2) non-abandonment. Children exist in the context of a family and therefore excellent care for the child must include attention to the needs of the family, including siblings. The principle of non-abandonment is an important one in pediatric palliative care, as many families report being well cared for during their child's treatment, but feel as if the physicians and team members suddenly disappear after the death of the child. Family-centered care requires frequent, kind, and accurate communication with parents that leads to shared decision-making during treatment, care of parents and siblings during end-of-life, and assistance to the family in bereavement after death. [http://pediatrics.aappublications.org/content/133/Supplement\\_1/S8.abstract](http://pediatrics.aappublications.org/content/133/Supplement_1/S8.abstract)

Noted in Media Watch, 1 July 2013, #312 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 June 2013 – **"To be a phenomenal doctor you have to be the whole package": Physicians' interpersonal behaviors during difficult conversations in pediatrics.** Eleven interpersonal behaviors were identified as important by parents [i.e., study participants]. The majority identified empathy in physicians as critical. Availability, treating the child as an individual, and respecting the parent's knowledge of the child were mentioned by almost half of parents. Themes also considered important ... were allowing room for hope, the importance of body language, thoroughness, going beyond the call of duty, accountability, willingness to accept being questioned, and attention to the suffering of the child. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0103>

Of related interest:

- *PEDIATRICS*, 2014;133(Suppl1):S24-S30. **'Communicating about prognosis: Ethical responsibilities of pediatricians and parents.'** Clinicians are sometimes reluctant to discuss prognosis with parents of children with life-threatening illness, usually because they worry about the emotional impact of this information. However, parents often want this prognostic information because it underpins informed decision-making, especially near the end of life. Despite understandable clinician concerns about its emotional impact, prognostic disclosure can actually support hope and peace of mind among parents struggling to live with a child's illness. [http://pediatrics.aappublications.org/content/133/Supplement\\_1/S24.abstract](http://pediatrics.aappublications.org/content/133/Supplement_1/S24.abstract)
- *PEDIATRICS*, 2014;133(Suppl1):S1-S7. **'Pediatric palliative care and pediatric medical ethics: Opportunities and challenges.'** The fields of pediatric palliative care (PPC) and pediatric medical ethics (PME) overlap substantially, owing to a variety of historical, cultural, and social factors. This entwined relationship provides opportunities for leveraging the strong communication skills of both sets of providers, as well as the potential for resource sharing and research collaboration. At the same time, the personal and professional relationships between PPC and PME present challenges, including potential conflict with colleagues, perceived or actual bias toward a palliative care perspective in resolving ethical problems, potential delay or underuse of PME services, and a potential undervaluing of the medical expertise required for PPC consultation. [http://pediatrics.aappublications.org/content/133/Supplement\\_1/S1.abstract](http://pediatrics.aappublications.org/content/133/Supplement_1/S1.abstract)

## Représentation de la sédation en situation palliative chez les pneumologues

*REVUE DES MALADIES RESPIRATOIRES*, 2014;31(1):48-56. In this medical population, already aware of palliative care issues, the majority of respiratory physicians know the definition, the indications for sedation and the principles of collective decision, but few are aware of the need of regular reappraisal of the sedation, to record it, and of its potential reversibility. There is, therefore, a clear need for regular and further training of clinicians to improve their professional practice. <http://www.sciencedirect.com/science/article/pii/S0761842513002155>

**N.B.** French language article.

Cont.

Representative sample of articles on palliative or terminal sedation noted in past issues of Media Watch:

- *INTERNATIONAL JOURNAL OF CLINICAL PRACTICE*, 2013;67(11):1086-1088. **'Clinical and ethical challenges of palliative sedation therapy: The need for clear guidance and professional competencies.'** This perspective analyzes challenges associated with professional decision-making about palliative sedation therapy and explores the recommendations of guidelines ... published in recent years. [Noted in Media Watch, 4 November 2013, #330 (p.8)] <http://onlinelibrary.wiley.com/doi/10.1111/ijcp.12227/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 8 April 2013 – **'From sedation to continuous sedation until death: How has the conceptual basis of sedation in end-of-life care changed over time?'** There is a pressing need to resolve the conceptual confusion that currently exists in the literature to bring clarity to the dialogue and build a base of commonality on which to design research and enhance practice of sedation in end-of-life care. [Noted in Media Watch, 15 April 2013, #301 (p.13)] [http://www.jpsmjournal.com/article/S0885-3924\(13\)00141-3/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00141-3/abstract)
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 December 2012 – **'Intentional sedation to unconsciousness at the end of life: Findings from a national physician survey.'** It has not been clear to what extent palliative sedation to unconsciousness is accepted and practiced by U.S. physicians. Although there is a widespread support among U.S. physicians for proportionate palliative sedation, intentionally sedating dying patients to unconsciousness until death is neither the norm in clinical practice nor broadly supported for the treatment of primarily existential suffering. [Noted in Media Watch, 17 December 2012, #284 (p.10)] [http://www.jpsmjournal.com/article/S0885-3924\(12\)00748-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00748-8/abstract)

### Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AUSTRALIAN NURSING & MIDWIFERY JOURNAL*, 2014;27(7):32. **'Media manipulation and the euthanasia debate.'** In October 2013, ABC News Radio conducted a web poll on the question: 'Should there be a national referendum on voluntary euthanasia?' Those responding to the poll had the option of answering a simple yes/no question, without qualifying their response. Just why the public broadcaster conducted the poll is a matter for speculation. <http://search.informit.com.au/documentSummary;dn=832560977308107;res=IELHEA>  
  
N.B. The authors of 'Confusion between euthanasia and other end-of-life decisions: Influences on public opinion polls' – *Canadian Journal of Public Health*, 2007;98(3):235-238 – observe that public opinion polls on euthanasia" should be interpreted in the light of the wording of the question. <http://journal.cpha.ca/index.php/cjph/article/view/820/820>
- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 5 February 2014 – **'Quebec's amended end-of-life law set for vote.'** Bill 52: An Act respecting end-of-life care has undergone 57 amendments in preparation for an anticipated vote mid-February by Quebec's National Assembly. The amendments ... define terms and allow changes to the Pharmacy Act. Bill 52 was approved in principal by a vote of 84-26 by Quebec's National Assembly on 29 October 2013. The revised bill is "tighter, crisper and clearer," says Jocelyn Downie, Professor in the Faculty of Law & Medicine at Dalhousie University, Halifax, Nova Scotia. "It's a good bill reflecting the will of the Quebec public." A "significant" amendment, according to Downie, requires patients to be at the end of their life before qualifying. However, Dr. Catherine Ferrier, a geriatric physician and president of the Physicians' Alliance for Total Refusal of Euthanasia says that amendment is not explicit enough because it fails to define what it means to be at the end of life. [http://www.cmaj.ca/site/earlyreleases/5feb14\\_Quebec-amended-end-of-life-law-set-for-vote.xhtml](http://www.cmaj.ca/site/earlyreleases/5feb14_Quebec-amended-end-of-life-law-set-for-vote.xhtml)

Cont.

- *MEDICAL LAW REVIEW* | Online – 28 January 2014 – '**Existential suffering and the extent of the right to physician-assisted suicide in Switzerland.**' In *Gross v Switzerland*, the European Court of Human Rights held by 4-3 majority that Switzerland had violated the right to decide when and how to die included in the right to respect for private and family life under Article 8 of the European Convention on Human Rights. To comply with the ruling, Switzerland must issue guidance detailing the circumstances (if any) under which physicians may lawfully prescribe lethal medication to competent individuals who have a voluntary and settled wish to die, yet whose suffering is not the product of a medical condition likely to result in death in the near future. <http://medlaw.oxfordjournals.org/content/early/2014/01/28/medlaw.fwt038.short>

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### Media Watch Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/2/media-watch/>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

#### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

#### **Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and [www.ipcrc.net/archive-global-palliative-care-news.php](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

#### **Canada**

ONTARIO | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

#### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> [Scroll down to 'Media Watch']

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

- *MEDPAGE TODAY* (U.S.) | Online – 4 February 2014 – **'Palliative care docs face "friendly fire."** Tragic cases like the California girl whose family fought to keep her life support after brain death was declared and the brain-dead, pregnant Texas woman whose family fought to remove life support have focused attention on the role of the healthcare team in making difficult ethical calls in the ICU. And yet, it's healthcare providers who are most likely to formally accuse other providers of "murder" and "euthanasia" related to palliative care, according to Lewis M. Cohen, MD, a psychiatrist at Baystate Medical Center in Springfield, Massachusetts. "Our society is pretty torn about what the right thing is to do," he told *MedPage Today*. "We are absolutely not immune to having the same doubts or having different beliefs that reflect our community." His group had published a 2012 survey of the physician members of a national hospice and palliative care professional organization that showed half of respondents had been accused by someone in the prior 5 years of murder, euthanasia, or killing when that wasn't their intent. <http://www.medpagetoday.com/HospitalBasedMedicine/Intensivists/44134>
- *PEDIATRICS*, 2014;133(Suppl1):S31-S36. **'Judging the quality of mercy: Drawing a line between palliation and euthanasia.'** Clinicians frequently worry that medications used to treat pain and suffering at the end of life might also hasten death. Intentionally hastening death, or euthanasia, is neither legal nor ethically appropriate in children. In this article, the authors explore some of the historical and legal background regarding appropriate end-of-life care and outline what distinguishes it from euthanasia. Good principles include clarity of goals and assessments, titration of medications to effect, and open communication. When used appropriately, medications to treat symptoms should rarely hasten death significantly. [http://pediatrics.aappublications.org/content/133/Supplement\\_1/S31.abstract](http://pediatrics.aappublications.org/content/133/Supplement_1/S31.abstract)
- *SOUTH AFRICAN MEDICAL JOURNAL*, 2014;104(2):102-103. **'Withholding or withdrawing treatment and palliative treatment hastening death: The real reason why doctors are not held legally liable for murder.'** Doctors who hasten the termination of the lives of their patients by withholding or withdrawing treatment or prescribing a potentially fatal palliative dose of medication satisfy the elements of intention and causation of a charge of murder against them. For policy reasons based on "society's legal convictions," such conduct is not unlawful if the patient consented to it or medical treatment would be futile or palliative treatment may hasten death. <http://www.samj.org.za/index.php/samj/article/view/7405>

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